

## **Patient Privacy Rights Testimony for the HIT Policy Committee & HIT Standards Committee PCAST Workgroup**

**February 15, 2011**

**We applaud the vision of the PCAST report regarding the necessity for effective consent and privacy technologies in the development of electronic health systems. The scenario on page 51 is one model for individual control that would create a trustworthy system.**

**We strongly agree that patients should be able to express privacy directives at a granular level, ensuring the preservation of privacy protections in state, federal, and common law.**

**Patient Privacy Rights and the PCAST report support the federal government's strong position on privacy. HHS Secretary Sebelius, FCC Chair Genachowski, FTC Chair Liebowitz, and National Coordinator Blumenthal have all stated individual control over personal information in electronic systems is imperative for public trust.**

However, we have the following serious concerns about the PCAST Report:

- 1. Implementing universal formats for data exchange without simultaneously designing privacy protections will lead to disaster.** Infrastructure for easy exchange of data that precedes protections will lead to widespread exchange and violation of patient privacy. The roadmap must be revised to explicitly require design for privacy at the outset.
- 2. Engineering large, secure, and privacy-preserving systems is remarkably difficult.** The roadmap must be revised to proceed slowly, with extensive adversarial testing at each stage to validate that desired privacy and security properties have been achieved.
- 3. De-identification of health data is always difficult and sometimes impossible.** Research has shown it's remarkably easy to re-identify supposedly anonymized datasets. The report does not adequately acknowledge this difficulty. Any vision of data exchange for research needs to grapple seriously with this issue, and incorporate explicit means to deal with it (e.g., adversarial testing and "glove box" response to queries rather than release of data sets).

**The public cares very deeply about privacy, and failure to protect privacy will impair adoption of the system.** Survey after survey shows the vast majority of the public wants to control the use and dissemination of their health information. More importantly, people act like they care; extensive evidence demonstrates that patients will put their health at risk to ensure that sensitive health information is private.

**We urge HHS to revise the roadmap and proceed cautiously to realize the public's expectation of individual control over health information and make the scenario on page 51 a reality.**